

# Quality of life: impact of chronic illness on the partner

Jonathan Rees MRCS<sup>1</sup> Ciaran O'Boyle BSc PhD<sup>2</sup> Ruairaidh MacDonagh MD FRCS<sup>1,3</sup>

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Patient quality of life is an increasingly important outcome measure in medicine and healthcare. It is now widely used in clinical trials and in patient management for assessing morbidity and the impact of treatment<sup>1</sup>. In the past, quality of life studies focused almost exclusively on changes in the quality of life of patients, but increasing attention is now being paid to the impact of chronic disease on carers. The ageing of the population and changes in medical practice resulting in shorter inpatient hospital stay and longer survival have substantially increased the burdens on carers, most of whom are partners<sup>2</sup>. In this paper, we examine research on partner quality of life and highlight some of the methodological challenges and the clinical implications. The background to this overview is collaborative research conducted in the Department of Urology in Taunton and the Department of Psychology at the Royal College of Surgeons in Ireland<sup>3–6</sup>. Further references were obtained by searching various databases (PubMed, CancerLit, PsycInfo, EMBASE and British Nursing Index) with the keywords 'quality of life, burden, impact, partners, caregivers and carers'.

## INSTRUMENTS FOR MEASURING PARTNER QUALITY OF LIFE

Early studies of carers focused mainly on carer burden. Zarit, Reever and Bach-Peterson<sup>7</sup>, in a pioneering study, investigated the correlates of caregiver burden and developed the Zarit Burden Interview, for many years the most widely used outcome measure in caregiver studies. Several measures of burden/strain have been developed for use among caregivers (not specifically partners) of geriatric patients with Alzheimer's disease<sup>8,9</sup> and Parkinson's disease<sup>10</sup>. Very few instruments have been developed specifically to measure carer quality of life and most investigators have been content to use modified patient questionnaires<sup>11,12</sup>. The Caregiver Quality of Life Index<sup>13</sup> contains items related to physical, emotional, social and financial wellbeing and has been shown to be both valid and reliable. This scale has been supplemented with a cancer-specific instrument<sup>14</sup>. Recently, disease-specific questionnaires have been developed and validated to measure morbidity in partners of patients with benign prostatic

enlargement and prostate cancer<sup>3,4</sup>. Uniquely, the prostate cancer questionnaire was developed simultaneously for both patients and partners, allowing administration of the same questions to both and thus facilitate direct comparison between patient and carer. An alternative to the questionnaire approach is the use of individualized measures such as the Schedule for the Evaluation of Individual Quality of Life, in which the partner defines and rates the quality of life areas important to him/her<sup>6,15</sup>. This has the advantage of not being disease-specific, and is therefore easily applied to a partner population.

## RESEARCH FINDINGS

Most studies assessing the impact of chronic disease on the partner/caregiver are cross-sectional and focus on elderly or psychiatric patients. In general, burden of care does seem to detract from carers' quality of life. For example, analysing reports from 256 carers (enrolled from a random sample of 1079 elderly individuals), Jones and Peters<sup>16</sup> found that caring for an incapacitated individual worsened health, impaired social and family life and increased stress, anxiety and depression. In an overview of carer quality of life in Alzheimer's disease, Guerriero-Austrom and Hendrie<sup>17</sup> found that many carers were both physically and mentally exhausted.

Perhaps the most striking research finding is a tendency for the partner's quality of life to be worse than that of the patient. Kornblith *et al.*<sup>11</sup> found that wives of patients with prostate cancer reported greater psychological distress than did their husbands. This finding is echoed in the work of Cliff and MacDonagh who designed a questionnaire specifically to measure psychosocial morbidity in prostate cancer patients and their partners<sup>3</sup>. Cancer-related distress was very common and significantly more severe in partners than in patients. Treatment-related worries and concerns about physical limitations and pain were also more common among partners. Weitzenkamp *et al.*<sup>18</sup> reported that the spouses of patients with spinal cord injuries had higher levels of depression, measured on the Center for Epidemiological Studies Depression Scale (CES-D), than did patients. The excess manifestations of depression were both somatic (appetite loss, sleeplessness) and affective (feeling 'blue', crying). Two studies looking at cancer patients in palliative home-care settings found that anxiety and depression were more common among partners<sup>19,20</sup>

<sup>1</sup>Department of Urology, Taunton and Somerset Hospital, Taunton, Somerset TA1 5DA, UK; <sup>2</sup>Department of Psychology, Royal College of Surgeons in Ireland, Dublin, Ireland; <sup>3</sup>Department of Surgery, University of Bristol, UK

Correspondence to: Jonathan Rees

and that many partners attempted to disguise their feelings. Caregivers of rheumatoid arthritis patients have also been shown to have lower health status scores than do healthy controls, particularly on emotional, mental health and general health status scales<sup>21</sup>. The level of morbidity in caregivers was only slightly less than that found in individuals with major depression.

#### Box 1 Problems for partners

Fear of the future  
 Depression and/or anxiety  
 Deterioration in partner relationship and/or sex life—decreased interest and enjoyment  
 Concern about suffering of patient  
 Implications of caregiving role on own health (particularly in the elderly)  
 Fatigue/sleep deprivation  
 Social disruption—either through looking after spouse or unwillingness to attend social functions alone  
 Financial difficulties—patient and/or partner unable to continue working, expense of private care and adaptations to home

Partners who are carers face numerous difficulties (Box 1). They may feel socially isolated and find it a struggle to combine the caregiving role with other responsibilities such as looking after the family. Caregiving can have great financial implications, especially for low-income families: one or both partners may be forced to give up work and costly alterations to the home may be required. Certain diseases present special challenges. Partners of patients with subarachnoid haemorrhage, for example, are often afraid to leave the patient alone, especially if they witnessed the initial event, and many partners express fear of having sex, particularly if the original haemorrhage occurred during sexual intercourse<sup>9</sup>. Spouses of patients with Alzheimer's disease describe a feeling of limbo—not widowed but not married either—which can persist for many years<sup>17</sup>. Partners of stroke patients found that the physical dependency, cognitive and communication deficits and psychological symptoms of their spouses meant that the spouse 'was not the same person'. This led to partners' describing a decrease in their marital satisfaction although, by contrast, most patients claimed they had no marital difficulties<sup>22</sup>. Another study, looking at partner morbidity in patients with benign prostatic enlargement, found that despite the benign nature of the disease 71% of partners were worried that their spouse had cancer and 59% were worried about the possibility of their partner requiring an operation<sup>4</sup>.

#### Carers' judgments

One important issue is the possible impact of the level of burden on the partner's perception of the patient. Partners

are often asked to make proxy decisions on behalf of patients, such as those who are incompetent by reason of mental retardation, mental illness, brain damage or dementia. These judgments can be influenced by the partner's own interests—that is, a partner may covertly request care and treatment options he or she wants for the patient, rather than those the patient would select if free to choose. This situation is likely to be compounded by the fact that the reliability and validity of doctors' and nurses' assessments of patient quality of life are even lower than those of partners or other proxy assessors<sup>23</sup>.

This dilemma is directly relevant to the clinical management and institutionalization of incompetent individuals, where it is often difficult to balance the needs of the patient and the needs of the partner. One example is the use of neuroleptic medication to reduce agitation in demented patients. Such treatment may well improve the partner's quality of life but often at the cost of decreased mobility, decreased engagement and further compromised cognitive functioning for the patient. Coen, having reviewed the studies addressing this issue, concluded that the level of burden and its impact on the quality of life of the partner must be taken into account when considering proxy judgments of patient quality of life<sup>6</sup>.

#### Factors influencing partner outcomes

Nijboer *et al.*<sup>24</sup> looked at factors associated with mental health outcomes in caregivers and divided them into three categories—characteristics of the caregiver, characteristics of the patient and characteristics of the care situation.

##### Characteristics of the caregiver

Partners bear a larger proportion of the burden of care than do other primary caregivers<sup>25</sup>. Caregiving seems to have a greater negative impact on female partners, especially younger ones<sup>26</sup>, although some studies have found males worse affected<sup>27</sup>. Partners who live alone with their spouse and those with lower incomes experience particular difficulties. In one study of partners of long-term stroke patients, the highest burden was found in those partners who themselves had unmet care needs (e.g. psychosocial support) and was not related to unmet care needs of the patient<sup>28</sup>.

##### Characteristics of the patient

Some studies have suggested a direct link between disease-severity and partner quality of life<sup>4,12</sup>, others not<sup>7</sup>. Research in the elderly suggests that the patient's mental health is more directly related to negative outcomes in the caregiver than is the patient's physical condition<sup>29</sup>. Coen *et al.*<sup>23</sup>, studying patients with Alzheimer's disease, found that carer

burden was better predicted by behavioural disturbance than by cognitive impairment.

### Characteristics of the care situation

Different care situations may have different consequences for the partner—for example, those that confine the partner to the house are more likely to have a negative effect on quality of life<sup>24</sup>. Situations involving personal tasks such as feeding or washing the patient are also perceived as more burdensome than those requiring non-personal duties such as doing the shopping<sup>25</sup>. When care is provided over a long period, the quality of the patient–partner relationship becomes increasingly important<sup>24</sup>.

### Positive aspects of caregiving

The consequences of caregiving are not exclusively negative. Many studies have identified positive aspects of the role, with partners describing increased self-esteem, pride, gratification and feeling closer to their spouse<sup>30,31</sup>. Axelsson suggests that the responsibility of caring for one's ill partner may confer a sense of 'meaning' to life and this in turn may augment global quality of life<sup>20</sup>. In a study of caregivers of multiple sclerosis patients, many of the partners reported positive aspects of their roles and described how being a carer had made them more caring towards others<sup>32</sup>. Nijboer *et al.* found an inverse correlation between the educational level of the caregiver and the positive impact of caregiving, those with lower levels of education being able to derive more self-esteem from caregiving<sup>24</sup>.

### CONCLUSIONS

Research in this area has tended to concentrate on caregivers in general and it is unclear to what extent partners differ from other caregivers or whether they are merely a subgroup of this broader classification. Partners will inevitably spend more time in the caregiving role than other carers and may have less social support. Ell *et al.*<sup>2</sup> have shown that partners, but not non-spouse carers, report the adequacy of social support as lower than do patients. Caregiving has both negative and positive consequences and couples respond differently. Partners sometimes feel a heavy responsibility and their involvement in providing care can have an enormous impact on their quality of life. However, many seem unwilling to reveal the true burden they are experiencing, perhaps for fear of seeming disloyal to their spouse.

Patients and partners may adapt at different rates to their situation and the type and rate of adaptation is likely to be influenced by various factors. There is increasing interest in what has been termed response shift. For example, when individuals experience a major change (e.g. in health state),

### Box 2 Implications for practice

Recognize partner burden and offer appropriate support  
 Partner should be present during consultation wherever possible  
 Address partner's concerns as well as patient's—may force couple to air issues not previously discussed  
 Assess carer's needs separately from patient's needs  
 Support for partner may delay or avoid hospital admission of chronically ill patients  
 Consider carer burden when listening to carers' assessments of patient quality of life  
 Provide written information wherever possible  
 Provide point of contact for patient/partner, e.g. support groups

their internal standards, their values or their conceptualization of quality of life can alter with it<sup>33</sup>. This adaptation is likely to occur in both patient and partner, but if it happens at different rates this can lead to a divergence in quality of life between them.

Since partners show high levels of psychological morbidity, it is important, clinically, that they be given an opportunity to express any difficulties they may be experiencing. This can be achieved in several ways (Box 2), most easily by inviting the partner to attend during medical consultations. Historically, partners have not been formally encouraged to accompany the patient and attendance rates of less than 10% have been recorded in some studies<sup>4</sup>. This may be because patients do not want their partners to be present or they may assume that partners are not allowed or expected to attend. Once in attendance, the partner should be involved in the discussion and participate in decision-making. Partners may be reluctant to express their own concerns in the presence of the patient and should then be offered a separate consultation; they will often appreciate information about support organizations. For example, the Carers National Association offers many services, including a telephone helpline and over 120 self-help groups across the UK. Specific information for carers of advanced cancer patients is also available from CancerBACUP, in particular

### Box 3 Support for partners

Carers National Association—helpline 0345 573369  
 Crossroads (Association of Care Attendant Schemes)—01788 573653; Scotland 0141 226 3793  
 CancerBACUP—020 7613 2121 or Freephone 0800 800 1234

the booklet *Coping at Home*. Crossroads (Association of Care Attendant Schemes) provides attendants to come into the home, offering respite care (Box 3).

A common reason for admission of patients to institutions is the need to relieve the family of its caregiving responsibilities<sup>20,34</sup>. If partners could be better supported, both in the home and by means of respite care, admission to

hospital or nursing home might often be delayed or even prevented. There is some evidence to support this hypothesis: in a study of late-stage lung cancer patients<sup>35</sup>, provision of home healthcare services allowed patients to maintain their independence for longer, while partners reported recovering sooner after the patient's death than did the partners of patients who had not received such home care. A key point is that social support and respite care must be provided in a regular and planned manner and not just as a response to crises in caring.

Several important questions need to be addressed by further research. Do simple interventions such as those outlined above substantially improve the quality of life of the caregiving partner? If partner quality of life is improved, to what extent does this impact on the wellbeing of the patient? The cost of improving partner support and providing respite care would be considerable, but might it be outweighed in the long term by reducing acute hospital admissions?

The recognition of high levels of partner morbidity demands a more holistic approach to caring for the chronically ill. In the past, the emphasis was on the patient alone, with particular attention to physical outcomes. A broader view must be taken which recognizes the effect of chronic illness on the physical and psychosocial wellbeing of the partner.

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